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AGE AT DIAGNOSIS IN CHILDREN WITH AUTISM SPECTRUM DISORDER

Salomone et al (post-print) *CCHD* (online 28th May 2015)

Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with ASD in Europe

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Key words

Autism; Autism spectrum disorder; Access to Health Care; Early Assessment; Age at diagnosis; Europe.

Key messages

- Age at diagnosis for autism spectrum disorder varies considerably across Europe
- Children with better language abilities, particularly females, were diagnosed later than non-verbal and minimally verbal children
- Awareness initiatives and integrated detection programs should be implemented to lower age at diagnosis

Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with autism spectrum disorder in Europe

Abstract

Background. Autism spectrum disorder (ASD) can in some cases be reliably diagnosed by age 2 years, but in community settings the mean age at diagnosis is often considerably higher. Later diagnosis has been found to be associated with lower symptom severity, lower parental socioeconomic status, and fewer parental concerns. Gender differences in age at diagnosis have been examined, with mixed evidence. **Methods.** We examined the association of child's verbal ability and gender, and parental education, with age at diagnosis in a large sample of young children with autism spectrum disorder in 18 European countries (N=1,410). **Results.** There was considerable variation in age at diagnosis across countries. Children with better communication skills were diagnosed significantly later than non-verbal and minimally verbal children. There was also a significant interaction of gender with verbal ability on age at diagnosis, in that females with complex phrase speech were diagnosed later than males with the same level of verbal ability. **Conclusions.** Our findings highlight the need to implement public awareness initiatives and training for professionals to promote early detection, and consequently early intervention, for autism spectrum disorder in Europe.

Key words

Age at diagnosis; autism spectrum disorder; Europe.

Child's verbal ability and gender are associated with age at diagnosis in a sample of young children with autism spectrum disorder in Europe

Introduction

Autism spectrum disorder (ASD) can in some cases be reliably diagnosed by age 2 years (Steiner *et al.* 2012), but in community settings the mean age at diagnosis is often considerably higher. A recent review of 42 studies published from January 1990 through March 2012 found that the mean age at diagnosis ranged from 38 to 120 months (Daniels & Mandell 2013). In these primarily US-based samples, later diagnosis was associated with lower symptom severity, lower parental socioeconomic status and fewer parental concerns. Some studies examined the association of age at diagnosis with gender, with mixed evidence. The importance of early diagnosis is its impact on families' access to early intervention, advice and support.

The aim of this study was to examine the association of child's reported verbal ability and gender, and parental education with age at diagnosis in a large multi-country sample of European young children with ASD.

Methods

We conducted a secondary analysis of data from an online survey on the use of interventions for young children with ASD, developed within the Cooperation in Science and Technology (COST)¹ Action 'Enhancing the Scientific Study of Early Autism (ESSEA)'

¹ The European project Cooperation in Science and Technology (COST) is an intergovernmental framework that supports the coordination of nationally funded research on a European level.

network. The ESSEA network, composed of over 80 scientists from 23 European countries, was established to promote capacity in ASD research and implementation science (Bölte *et al.* 2013; García-Primo *et al.* 2014; McConachie *et al.* 2015). The survey, which asked about current use of conventional intervention (such as speech and language therapy, applied behavioural analysis; see Salomone *et al.* 2015a, in press), as well as use of medication and complementary and alternative medicine (see Salomone *et al.* 2015b, in press), was distributed via parent support associations through the ESSEA network in 20 European countries and was open for 45 days. Two initial questions were designed to filter out participants who did not meet the inclusion criteria: to be a parent/caregiver of a child a) with ASD; and b) aged 7 or younger. Two countries (Austria and Sweden) were excluded from the study as the number of participants recruited within the planned timeframe was too low (Austria: $n = 1$; Sweden: $n = 5$). The final dataset included data from the following countries: Belgium, Czech Republic, Denmark, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, the Netherlands, Norway, Poland, Portugal, Romania, Spain, the former Yugoslav Republic of Macedonia and the United Kingdom.

Ethical approval was given by the Research Ethics Committee of the Faculty of Children and Learning, Institute of Education, London, UK (IOE/ FPS 385). Informed consent was obtained. To reduce the potential for confounding of chronological age on the relationship between verbal ability and age at diagnosis, a restriction strategy was implemented to ensure that all participants were at an age when complex phrase speech may potentially be present. Therefore only data from children aged ≥ 4 years were included ($N=1,410$; 81.8% male). Information on child's verbal ability and parental educational level was available for 1,245 respondents. Of these, 16% of the children were non-verbal, 27% used single words or simple phrases and 57% used complex phrases. Parents' education was reported as degree or postgraduate qualification in 63% of the sample.

Results

The mean age at diagnosis was 42.16 months ($SD=13.42$); one-sample t tests were used to compare the mean age at diagnosis in each country with the mean of all of the remaining countries ($N=1,410$; Table 1).

---- Table 1 about here ----

A three-way independent ANOVA was conducted to examine the effect of child's verbal ability (non-verbal; minimally verbal; complex phrases), gender, and parental education (high school diploma and below; degree/post graduate) and their interactions on age at diagnosis ($N=1,245$). There was a significant main effect of level of verbal ability on age at diagnosis, $F(2, 1245) = 56.871, p < .001$; the effect size was small (partial $\eta^2 = .08$). The Bonferroni post hoc test revealed that the age at diagnosis was significantly higher for children who used complex sentences ($M=47.13, SD=.65$) than both non-verbal children ($M=35.37, SD=1.18$) and minimally verbal children ($M=37.93, SD=.88$), both $ps < .001$. The age at diagnosis of non-verbal children and minimally verbal children were not significantly different from each other. The main effect of gender on age at diagnosis was not significant, $F(1, 1245) = .286, p = .593$. However, there was a significant interaction between verbal ability and gender on age at diagnosis, $F(2, 1245) = 3.519, p = .030$; the effect size was small (partial $\eta^2 = .01$). In children with complex phrase speech, age at diagnosis was higher for females ($M=48.57, SD=1.18$) than males ($M=45.69, SD=.55$), $F(1, 1245) = 4.869, p = .028$. The effect of gender was not significant for non-verbal ($F(1, 1245) = 2.294, p = .130$) or minimally verbal children ($F(1, 1245) = .344, p = .558$). The main effect of parental educational level was not significant, $F(1, 1245) = .199, p = .656$; nor were the interactions

between parental educational level and verbal ability ($F(1, 1245) = .965, p=.381$) or gender ($F(1, 1245) = .154, p=.695$).

---- Figure 1 about here ----

Fig. 1 Interaction of gender and verbal ability on age at diagnosis (N=1,245)

Discussion

We report the first data on factors associated with age at diagnosis in a large multi-country European study. Age at diagnosis varied considerably across countries in this sample. Children in Portugal, Spain, Italy, Poland and Romania were diagnosed at a significantly lower age than in the rest of the countries, whereas in the Netherlands, Germany, Hungary, Denmark and Belgium the age at of diagnosis was significantly higher. This seems to reflect concerns about the difficulty of obtaining a timely ASD diagnosis, even in medically well-served areas of Europe (such as in Germany; Noterdaeme & Hutzelmeyer-Nickels 2010). However, differences across countries need to be interpreted with caution, as the recruitment method employed in this study (online survey advertised through parents associations) might have been prone to selection bias and differences in the outreach of each national organisation might have influenced sampling.

Consistent with previous findings of higher age at diagnosis for less impaired children or children with an Asperger syndrome or a PDD-NOS diagnosis (Mazurek *et al.* 2014; Mandell *et al.* 2010; Wiggins *et al.* 2006), we found that children with better verbal abilities tended to be diagnosed later. We also found a significant interaction of gender with verbal ability on age at diagnosis, in that females with complex phrase speech were diagnosed later than males with the same level of verbal ability. This finding is consistent with previous reports of delays in the diagnostic process for females (Russell, *et al.* 2011; Wiggins *et al.*

2006), and particularly for girls with better language abilities (Giarelli *et al.* 2010). In our sample age at diagnosis did not vary by parental educational level. Out of the 11 studies reviewed by Daniels & Mandell (2013) examining the association between measures of socioeconomic status (SES) and age at diagnosis, 6 found no association (of these, 4 studies used samples from the United States, one from England, one from Germany). The reasons underlying these mixed findings are unclear and are likely to reflect systemic differences in the provision of primary diagnostic services across countries.

These findings should be interpreted in the context of a number of limitations. Due to the recruitment method, our sample cannot be considered representative of the general population of children with ASD. As per inclusion criteria for the survey, all children had already received an ASD diagnosis and were aged <7 years, hence the reported age at diagnosis is likely to be lower than for the total population of individuals with ASD, some of whom will be identified at a later age. Furthermore, the extent of the disadvantage for children with better communication abilities in receiving a timely diagnosis, particularly if they are female, is also likely to be underestimated. Public awareness initiatives as well as training for professionals should be put in place to promote early detection of ASD and access to intervention across Europe (Oosterling *et al.* 2010).

Conflict of interest

On behalf of all authors, the corresponding author states that there is no conflict of interest.

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AGE AT DIAGNOSIS IN CHILDREN WITH AUTISM SPECTRUM DISORDER

Table 1 Age at diagnosis by country: comparisons of mean age in each country with mean age in all of the remaining countries

| | N | M (SD) | t (df) | p | effect size* |
|----------------|--------------|----------------------|--------------|-------|--------------|
| Portugal | 113 | 33.53 (11.66) | -8.550 (112) | <.001 | 0.63 |
| Italy | 88 | 35.73 (13.02) | -4.944 (87) | <.001 | 0.47 |
| Spain | 186 | 36.66 (13.54) | -6.375 (185) | <.001 | 0.42 |
| Romania | 44 | 37.55 (11.23) | -2.813 (43) | .007 | 0.39 |
| Poland | 60 | 37.85 (11.7) | -2.980 (59) | .004 | 0.36 |
| Macedonia | 22 | 39.59 (10.53) | -1.162 (21) | .258 | |
| Czech Republic | 81 | 42.21 (10.26) | .044 (80) | .965 | |
| Norway | 24 | 42.5 (14.37) | .119 (23) | .906 | |
| Iceland | 46 | 42.59 (10.9) | .278 (45) | .782 | |
| France | 154 | 42.76 (12.75) | .662 (153) | .509 | |
| United Kingdom | 92 | 43.28 (12.42) | .929 (91) | .355 | |
| Finland | 41 | 44 (11.55) | 1.053 (40) | .299 | |
| Belgium | 96 | 45.71 (13.33) | 2.800 (95) | .006 | 0.28 |
| Ireland | 22 | 46.59 (13.45) | 1.570 (21) | .131 | |
| Hungary | 106 | 47.88 (12.37) | 5.150 (105) | <.001 | 0.45 |
| Germany | 79 | 48.44 (10.98) | 5.387 (78) | <.001 | 0.52 |
| Netherlands | 90 | 50.02 (12.22) | 6.524 (89) | <.001 | 0.57 |
| Denmark | 66 | 50.17 (14.4) | 4.741 (65) | <.001 | 0.51 |
| <i>Total</i> | <i>1,410</i> | <i>42.16 (13.42)</i> | | | |
| *Rosenthal's r | | | | | |